

A Primary-care-led Diabetes Service: Strengths, Weaknesses, Opportunities and Threats

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In October 1997 the NHS Executive issued a Health Service Guideline entitled *Key Features of a Good Diabetes Service*,¹ intended as a framework against which health authorities could assess the adequacy of the service provided locally. This document explicitly stated that, in addition to providing structured care driven by best evidence and reflecting local needs, the service should be 'primary care based'. This reflects an overall strategic vision for a National Health Service in which secondary care exists to support, and respond to, the agenda of primary care.^{2,3} But what has primary care got to offer?

Primary care has been defined as *first-contact* care, delivered by *generalists*, dependent (increasingly) on *teamwork*, which is *accessible* (both geographically and culturally), *comprehensive* (interested in old as well as new problems), *co-ordinated*, *population-based* (there is responsibility for 'the list' as well as the individual patient) and activated by *patient choice*.⁴ The general practitioner is no mere gatekeeper; he or she is, first and foremost, a provider (only a tiny minority of GP-patient encounters result in referral to secondary care) and a sophisticated triage system (acting variously as an accelerator, a brake and a filter for the material of secondary care), as well as an advocate and information-giver.

The difference between primary and secondary care has been summed up by Heath: 'in secondary care diseases stay, but patients come and go, whereas in primary care patients stay but diseases come and go'.⁵ Marinker has suggested that the hospital specialist sees his or her task as largely concerned with 'distinguishing the clear message of the disease from the interfering noise of the patient as a person', while the vocation of the primary care clinician is to focus on the holistic aspects of care and the complex physical, psychological, emotional and cultural factors that make up the ongoing, lived experience of health and illness.⁶

It is important not to be constrained by these stereotypes. Hospital teams can, and do, consider both co-

morbidity and the impact of diabetes on patients' lifestyles; these teams, perhaps particularly the diabetes specialist nurses, provide excellent psychosocial support for many patients. Conversely, 'leading edge' primary care teams have pioneered the development of a diabetes subspecialty within general practice, with perhaps one doctor and one practice nurse acquiring special expertise and offering comprehensive care for all but the most complex of diabetes-related problems.⁷ Nevertheless, continuity of care and long-term support for the challenge of living with diabetes are an acknowledged strength of primary care⁸ and the potential lack of specific disease-based expertise is a weakness we would be foolish to ignore.

At the inaugural conference of Primary Care Diabetes UK, I presented case studies of three patients. The first was Sharon, a 15-year-old girl with so-called 'brittle diabetes' who had just spent 9 months as an inpatient in a leading metabolic unit. Although Sharon was, on the face of it, unequivocally a 'secondary care' patient, the change in the course of her diabetes, objectively measured by a dramatic fall in her HbA_{1c} levels over the next 3 years, came as a result of a change in her self-respect and motivation on an 'outward bound' holiday with a group of peers and a general practitioner.

I also presented Zabeda, a 55-year-old Bangladeshi living in the East End of London who has multiple complications including cataracts, hypertension, hyperlipidaemia, and effort angina. Zabeda's damp council flat is three floors up with a broken lift. Her Bangladeshi GP practises from a two-room lock-up in Tower Hamlets, where the prevalence of known diabetes in this ethnic group is 20 %. In this surgery, there are always at least 20 people on the floor in the waiting room but there is no nurse, no treatment room, no books, and no safe place to store drugs and equipment. Above all, there is no *time*—either for addressing the patient's educational agenda, or for self-reflection and professional development of the doctor. But, unlike anyone at the hospital, Zabeda's GP speaks her language.

Zabeda, who exemplifies the problems of ethnic Asians in poor inner-city areas,⁹ prefers to consult her general practitioner than go to hospital. She and her contemporaries can look forward to a brighter future only when the standard of primary care in the inner cities is brought

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up to that of the best practices in the shires, with the added dimension of appropriate provision for minority ethnic groups.^{10,11}

Finally, I presented Derek, who is 68 and has had diabetes for 2 years, along with obesity, hypertension and early microvascular damage. The clinic doctors told him that his inability to control his weight and keep his diabetes under control was due to lack of willpower, so he stopped going to clinic. As Griffin's comprehensive review on defaulters¹² shows, if we fail to consider the invisible Dereks of our target population, the laudable objectives of the St Vincent Declaration¹³ will remain a pipe dream. Derek's problems may begin to be addressed if specialists and general practitioners consciously and explicitly avoid the collusion of anonymity that results in duplicated but haphazard care and the collection of the biomedical dataset at the expense of the patient's dignity.

The squeaky-clean model of shared diabetes care, in which all professionals know and agree on their roles, and both patients and information flow smoothly between different health care sectors, has never happened¹⁴ and never will. It could be argued that any diabetes service should be evaluated not only in terms of what facilities it provides for the typical, uncomplicated or compliant patient, but also by how well it serves the atypical, 'noncompliant', invisible and disempowered members of the community.

Several articles in this supplement underline both the problems and the opportunities born of primary care's increasing involvement with diabetes. Two original articles report feasibility studies of different methods of delivering an area-wide retinal screening programme. A paper from Sweden introduces the 'Bäcklund bus'—a mobile retinal camera taken to primary care centres and offering feedback on screening results directly to primary care teams.¹⁵ They conclude that this model compares favourably with 'top-down' programmes in terms of both process (population coverage) and outcome (sight-threatening lesions successfully detected and treated).

Burnett and colleagues describe their experience with a retinal screening programme delivered by high street optometrists in an inner-city area of London.¹⁶ This scheme used a central register for prompted recall, and achieved high levels of coverage given the realities of inner-city care. Elsewhere in this supplement, however, two academic general practitioners join forces with a consultant diabetologist to argue that the case for centrally run (as opposed to practice-based) databases for the registration and recall of patients with diabetes is unproven.¹⁷

Petrie *et al.* discuss the relentless epidemic of 'Syndrome X'—the cluster of hypertension, glucose intolerance, dyslipidaemia and obesity—in the developed countries of the world, and present a sobering overview of the failure of diabetologists, metabolic experts and general physicians to address the problems of obesity, inactivity and insulin insensitivity in their patients.¹⁸ Primary care teams have yet to demonstrate better

success in this field, but with exciting new research developments in negotiation between clinicians and patients for behaviour change in primary care¹⁹ and in primary-care-based prescription-for-exercise schemes and similar initiatives^{20,21} the future looks guardedly promising.

Pierce suggests how GPs might get involved in the research aspects of diabetes care, perhaps through primary care research networks, and offers practical advice which hospital teams would do well to heed if they plan to recruit primary care teams into research studies.²² Kinmonth offers some provocative thoughts on where primary-care-focused diabetes research might lead.²³ New opportunities for research as well as service delivery by motivated and well organised 'leading edge' primary care teams is indeed an exciting prospect. But the experience of two enthusiastic and well motivated teams in Manchester²⁴ and Lanarkshire²⁵ demonstrate the difficulties inherent in delivering care in the real world, particularly the attempt to 'roll out' and maintain an area-wide programme of structured care in practices *not* at the leading edge in diabetes.

The huge variation in data capture in the Lanarkshire and Manchester studies reported in this issue underlines the fact that although many GPs in the UK are enthusiastic about diabetes care, there are others who feel that this is yet another example of 'dumping' the workload of secondary care onto an overburdened and inadequately supported primary care sector.²⁶ But there is now an epidemiological imperative. The incidence of diabetes is rising sharply; hospital clinics are already full to bursting and patients are rightly demanding competent, consistent, accessible and culturally sensitive care. Training and remuneration systems for GPs, practice nurses and district nurses need to change to ensure that all primary health care teams are adequately resourced, appropriately trained and properly supported by the specialist sector. Were this to occur, motivation to provide the best care would undoubtedly increase.

The 3 case histories described above demonstrate that practitioners in both primary and secondary care need to reflect hard, not on what works in an ideal or theoretical system of care, but on what predictably fails to work, given the complexities of the real world, the deficiencies of real systems and real health professionals, the different needs of individual patients, and the limited resources currently on offer for the iceberg of unmet need in diabetes.

The inadequacies in the provision of diabetes care in the UK will not be redressed simply by sounding the trumpet for a primary-care-led system, nor by the formation of political factions to protect the traditional territory of the diabetologist. They may, however, begin to be addressed by ensuring that diabetes services are designed (or, more usually, redesigned) from the point of view of the user, and that packages of care are tailored to the individual patient and not to a rigid district-wide or clinic-based protocol. This organisational challenge

should surely be top of the research agenda in the 21st century.

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